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Integrating Users in an Interactive Video Education Project: Reframing the Patient-Centered Strategy of a Cystic Fibrosis Centre

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Integrating Users in an Interactive Video Education Project: Reframing the Patient-Centered Strategy of a Cystic Fibrosis Centre

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Abstract:

This article reports on the formative evaluation of WebPEP ("Web-Based Patient Education Program"), an interactive video education project at ErasmusMC–Sophia Children's Hospital (SCH) in Rotterdam, the Netherlands. Through monthly live webcasts, doctors, nurses, psychologists, and other healthcare professionals affiliated to SCH's Cystic Fibrosis Team gave presentations on medical and psychosocial aspects related to cystic fibrosis (CF). These webcasts were first intended to educate and be educational to children between the ages of twelve and eighteen, but during the first year of the project they failed to attract this specific group. Instead, they generated unexpected enthusiasm among parents of young patients. The central question in this article is: How were patients "integrated" in the development of the WebPEP application? We show how the project's initiator reacted to the lacking participation by prospective users: informed by the evaluation, he gradually shifted his attention from live interaction to the expansion of the video library, where the webcasts were stored for on demand viewing. Based on interviews and participant observations, we describe how the initiator reconfigured the WebPEP application and its users, and thereby reframed the CF Centre's online patient education strategy. We discuss the importance of investigating the prospective and actual use of patient-centered e-health (PCEH) applications, and argue that a single technological artefact can be involved in different, coexisting practices of patient-centeredness. We conclude with a reflection on how formative research methods can contribute to the development of PCEH.

Keywords: patient-centered education; integrating users; prospective and actual use; framing; formative evaluation

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I. INTRODUCTION

This article discusses an e-health project that failed to reach its prospective users during its first year, while generating unexpected enthusiasm among a different group instead. The project in question is WebPEP, an online education program for cystic fibrosis (CF) patients of the ErasmusMC–Sophia Children’s Hospital (SCH) in Rotterdam, the Netherlands. Viewed by its initiator¹ as a possible solution to problems in CF education in youth, the program was largely neglected by the patients it was aiming for: children with CF between the ages of twelve and eighteen. Meanwhile, it was being embraced by parents of young CF patients—a group that had not been taken into account during the development of the project. The rift between prospective and actual users came to light during the evaluation of the pilot, and initially seemed to indicate that the project was failing.

The central question in this article is: How were patients “integrated” in the WebPEP application? Starting from the theoretical notion of “configuring the user,” we describe the prospective and actual use of the application, and reflect on how the project’s initiator reframed the application along the way. In this process, a reconfiguration of WebPEP and its users occurred. We argue that the changing role of the application in relation to patient education led to different practices of patient-centeredness, as well as different enactments of patient-centered e-health. The article concludes with a brief reflection on the value of the evaluation method applied in our study.

II. THEORETICAL FRAMEWORK

The design and development of technological objects inherently takes place in relation to users. Whether consciously or unconsciously, designers and developers anticipate the use of their creation, and therewith “configure” prospective users in their work [Akrich, 1995; Oudshoorn and Pinch, 2005; Oudshoorn, Rommes and Stienstra, 2004; Woolgar, 1991]. The notion of “configuring the user” entails a mutual integration process of users and artefacts, rather than a straightforward or fully predetermined alignment between them. From this perspective, “the success and failures of technologies [are conceptualized] mainly in terms of the extent to which designers adequately anticipate users’ skills and behavior” [Oudshoorn and Pinch, 2005]. While this approach has been criticized for prioritizing the agency of designers over that of users [Oudshoorn and Pinch, 2005], it allows us to reflect on the identities ascribed or conferred to users before and after significant interventions in the project.

To discuss the different types of interaction between the WebPEP application and its users throughout the evaluation period, we adopt Madeleine Akrich’s notion of “script.” Akrich’s use of this term is embedded in actor-network theory, which is based on the premise that human and nonhuman “actants” participate in the creation of heterogeneous sociotechnical networks [Akrich, 1992]. Akrich borrowed the term from semiotics to convey the idea of designers “*inscribing*” [a] vision of (or prediction about) the world in the technical content [of objects]”; and that in turn, the latter “define a framework of action together with the actors and the space in which they are supposed to act” [Akrich, 1992; italics in original]. Although users can bypass or ignore the roles envisaged by designers, or indeed define different roles of their own [Akrich, 1992], alternative repertoires of action are not endless: technological objects always impose limits and constraints on their use.

III. BACKGROUND OF THE CASE STUDY

Cystic fibrosis is a chronic and life-threatening lung disease. It causes the buildup of mucus in the lungs, and can also affect the pancreas, the liver, and the intestine. It can lead to lung infections and serious digestion problems, and requires intensive treatment from the time of diagnosis, which in many cases is established during early childhood.² Extensive knowledge and discipline are required by patients and their parents or caretakers to put the treatment in practice, which makes education indispensable.

At SCH the treatment strategy and the approach to CF education in youth have been subjected to considerable change in the 1990s and 2000s. Until the mid-1990s patients were instructed about therapy, diet, and psychosocial issues related to CF during outpatient visits at the CF Centre. This was perceived as a highly inefficient arrangement by members of the CF Team: they were repeating the same instructions to each individual patient while facing busy consulting hours and great time pressure.

¹ The initiator of WebPEP is a professor of pulmonary diseases and chairman of SCH’s CF Centre.

² More information: PubMed Health (<http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0001167/>).

In the mid-1990s, the CF Team started offering yearly group briefings at SCH. Meetings were open to patients and their parents, and greater attention was given to the prevention of lung deterioration. Around the same time, however, epidemiological studies were indicating that group gatherings could lead to the transfer of bacterial infections between CF patients.³ In the wake of growing evidence on this subject, the UK Cystic Fibrosis Trust Control of Infection Group published new guidelines [2001, 2004] for group gatherings. Similar measures were taken in other countries, and around 2005 the CF Team decided to exclude patients from their yearly briefings.

To compensate for what they perceived as a lack of attention to CF education, the CF Centre started issuing a biennial newsletter for patients. However, contact moments with patients were still regarded as too infrequent, and CF Team members found that the education they provided during consultations was too fragmented and not adequately coordinated. To tackle these issues and bypass the problem of physical group gatherings, the CF Centre sought a Web-based solution.

In 2006 the parents' association of CF patients and Stichting Vrienden van het Sophia (Friends of the Sophia Foundation) raised funds to enable CF education via the Internet. The initiative was named WebPEP, short for "Web-Based Patient Education Program." One of the main expectations of WebPEP was that it would allow group gatherings to take place "virtually" and more frequently. In a meeting we had with the project's initiator in May 2010 he explained his vision as follows:

"WebPEP enables us to offer a more tailored type of education. We have an annual educational meeting, which is primarily attended by parents of young children who don't know much about it. And the entire team is present. Many participants come from [far away], so it's a very inefficient way of providing education. And those who are not attending, like the Moroccan family from Rotterdam-Zuid [a largely immigrant, poor area of the city] are probably the ones that need it most. We are looking for ways to provide more education to specific groups, such as adolescents, who represent a high-risk group."

In that meeting, the initiator also stressed the importance of interacting with patients. Drawing from his own professional experience, he explained that doctors gain a better picture of their patients through extensive interaction, and that this ultimately leads to better treatment:

"They [the CF patients] are not CF specialists. They feel things, but feelings tell you very little about your health in five years. [...] It's very difficult for us to truly empathize with our patients, and to understand what they really think. The more interaction moments you have, the greater the chance that someone will open up to you, and ask that strange question that makes you realize: 'Huh?! What's that strange idea they have in their mind?!' [...] You need to strike the right chord in order to commit them to their treatment. And in each person it's a different chord."

Expectations of improved CF treatment through regular online interaction were embedded in a broader discourse on patient empowerment. In the initiator's view, WebPEP would enable a type of CF education that was more tailored to the needs and desires of the audience *because* it allowed for interaction with the latter. Patients would be in the position to actively contribute to the program with their questions and remarks, and were expected to feel more in charge of their own treatment than if they were attending the presentations as mere "spectators." The initiator hoped that the webcasts—aimed at patients between the ages of twelve and eighteen—would specifically draw the attention of adolescent patients; he argued that they are more susceptible to non-adherence to therapy than younger patients.

The initiator's view on patient empowerment is congruous with the notion of patient-centered communication (PCC), which is generally described as a set of specific behaviours in doctor-patient interaction [Epstein et al., 2005; Saha and Beach, 2011] and an overall style of practice in which the delivered care is "concordant with the patient's values, needs and preferences" [Epstein et al., 2005; see also Laine and Davidoff, 1996; Mallinger, Griggs and Shields, 2004]. By extension, the WebPEP application can be said to qualify as a form of patient-centered e-health (PCEH), at least in terms of its intended use: the patient-centeredness resides in the prospect of enabling patients and providers to reciprocally share information anywhere and anytime⁴ [cf. Dawson, Tulu and Horan, 2009].

The WebPEP approach to patient education is not unique; similar webcast technologies have been applied to CF education⁵ and other chronic diseases.⁶ Other notable "patient-centered" solutions for online education include

³ One of the earliest publications on this subject is Govan et al. [1993].

⁴ Although live interaction in WebPEP takes place on preset times, users can access the application's video library at their own convenience.

⁵ For example, see the Cystic Fibrosis Foundation webcasts [<http://www.cff.org/LivingWithCF/Webcasts/>] (current Mar. 4, 2013).

⁶ For example, see the Cleveland Clinic webcasts [<http://www.clevelandclinic.org/health/webcast/>] (current Mar. 4, 2013).

educational games, which aim at similar goals (such as improving therapy compliance or inducing a healthy lifestyle) by different means.⁷ A distinctive functionality of the WebPEP application is that it allows patients to share their ideas, comments, and feedback with the presenter through live interaction. In the following section, we review the technical and organizational arrangements behind this interaction.

IV. CASE DESCRIPTION

The technical contours of the WebPEP project were first sketched in 2009, when a partnership was established with Zorgportaal Rijnmond (www.zorgportaalrijnmond.nl), a newly developed portal for healthcare and well-being in the Rotterdam Rijnmond region. With the support of Zorgportaal Rijnmond stakeholders, various applications by different vendors in the Netherlands were researched. A contract with a company specialized in online video education platforms was signed in the summer of 2010; subsequently, numerous functional and security tests were performed. In November 2010 the first WebPEP webcast with patients took place, making it the first periodic and interactive video education program for patients to comply with Dutch privacy and security guidelines in medical care.

WebPEP consists of a periodical series of webcasts presented by doctors, nurses, psychologists, and other healthcare professionals affiliated to the CF Centre. The webcasts revolve around therapy compliance and psychosocial implications of CF in youth. They are made available through the online video application ZorgInfoTV on Zorgportaal Rijnmond. Access to the webcasts (either for live participation or “on demand” viewing) is restricted to the CF patients of SCH. Through letters and email messages they are notified about the topic, date, time, and presenter of upcoming webcasts.

The webcasts are produced at the TV studio of SCH, which features technical equipment such as a camera, spotlights, microphones, and an audio mixing table. An online recorder (provided by the contracted vendor) enables live interaction between the presenter and participants as well as storage in the ZorgInfoTV video library (see Appendix A, Figure A–1, for a schematic representation of how WebPEP participants log in to the application). During the live webcasts, the technical staff at the studio minimally comprises of an audio engineer and a cameraman (both employed by SCH) and an operator for the online recorder (delegated by the vendor).

The production process follows a standardized scenario that was developed during the first months of the project. To confer a consistent “look and feel” to the webcasts, the same visual setup is used throughout the project. A full-scale rehearsal takes place during the last hour before a webcast goes live; this allows the presenter to get acquainted with the setting, while the technical staff make audio and lighting adjustments and test whether the PowerPoint slides are displayed correctly. The slides are shown alongside the video screen during the presentation; the presenter uses a laptop to navigate through them (see Appendix A, Figure A–2, for a screen capture of the WebPEP interface). Some presenters also use a graphics tablet, which enables them to hand-draw arrows and markings on their slides during the presentation.

Presenters take turns in giving educational presentations on medical and psychosocial aspects related to CF. Topics vary from how enzymes work to the yearly patient examination (see Appendix A, Table A–1); the content of the presentations is targeted at an audience of twelve years and older. Presenters are asked to contain the tempo of their speech and the length of their presentation, to avoid difficult words, to use an appropriate tone of voice, and to assume a child-friendly demeanour. To improve their presentation skills in front of a camera, the initiator of WebPEP organized several training sessions under supervision of a professional theatre director, who has extensive experience with theatre productions for children.

During the webcast, presenters invite participants to submit questions and to participate in real-time online polls; these functionalities are exclusively available during live webcasts. Participants can enter their questions in a text box and use a dedicated function to answer poll questions. In accordance with privacy guidelines in Dutch medical care, participants do not appear on video and remain anonymous to their fellow participants. Their questions are only visible to the moderator, who is seated next to the presenter. The moderator reads and selects incoming questions on his/her laptop and forwards them to the presenter (see Appendix A, Figure A–3, for a schematic representation of how the presenter, participants, and moderator interact during live webcasts).

The login procedure for the application is based on a ‘single sign-on’ principle on the portal. Upon their first visit to Zorgportaal Rijnmond, WebPEP participants need to create a personal account by providing their name, age, telephone number, and email address. After this registration process, they are required to log into the portal with

⁷ Information obtained from Webicina.com [<http://www.webicina.com/about/who/>] (current Mar. 4, 2013).

their personal DigiD code (a digital identity code for various online government services in the Netherlands).⁸ Through this step, the system verifies the authenticity of the user, and checks whether access to ZorgInfoTV is authorized. Upon login, participants enter a secure Web environment (https://) where links to several ZorgInfoTV services are provided. WebPEP is the oldest of these services, and contains the largest video library (twenty-five webcasts by March 2013). Webcasts go “on air” approximately one minute before the official start of the presentation, thus allowing participants to attend from the start.

V. RESEARCH METHOD

We conducted a formative evaluation of the WebPEP project. This method can be distinguished from summative evaluation techniques in that it takes place during the development phase of a project rather than *a posteriori* [Scriven, 1967]. Starting from November 2009, we assessed the course of the project and made interventions throughout the process. There were no specific results or parameters to be attained or compared,⁹ and the evaluation had an explorative character. A research proposal was submitted to the Medical Ethics Committee of the Erasmus Medical Center prior to fieldwork, after which the first author was granted permission to interview patients of SCH. He attended meetings at Zorgportaal Rijnmond (where a project leader was appointed to develop the ZorgInfoTV application) and assisted in the production of five webcasts, which allowed him to conduct participant observations at the TV studio of SCH.¹⁰ Numerous formal and informal encounters took place with the project's initiator and members of the CF Team; the first author also attended an educational meeting for parents of CF patients at SCH (March 2011) and a camera training session for presenters.

WebPEP participants were invited to contribute to the study at the end of several webcasts; for this purpose, they also received requests by email, which were sent out by the CF Team. Between May and August 2011 the first author conducted semi-structured interviews with thirteen WebPEP participants; some were recruited at the educational meeting at SCH, whereas others were initially contacted by telephone using a list provided by the CF Team. The first author was also granted access to the vendor's log data generated by the software platform underlying the ZorgInfoTV application.

Through regular debriefings we provided feedback and suggestions to the ZorgInfoTV project leader and to members of the CF Team, including the initiator of WebPEP (who also featured as a presenter in several WebPEP webcasts). The first author wrote a report after each webcast, which included technical and productional issues to resolve, as well as raw “activity data” related to users. Reports were forwarded to the ZorgInfoTV project leader, the Zorgportaal Rijnmond program manager, and the WebPEP initiator. In April 2011 he sent them a preliminary report based on the first four webcasts. The final evaluation report (August 2011) was based on the first eight webcasts, and was formally presented to members of the CF Team, the project leader of ZorgInfoTV, and the project manager of Zorgportaal Rijnmond in October 2011.

Being closely involved in the development of WebPEP and the ZorgInfoTV application, the first author was able to observe the stakeholder's response to his feedback. They shared their views and preoccupations on the project's progression with him, particularly in relation to user-related insights from the evaluation. Insights from these interactions were shared in the research team and analysed jointly. Inherent to the interventionist character of the evaluation, the authors' research was part and parcel of the course of the project's development.

VI. EMPIRICAL FINDINGS

The evaluation generated qualitative and quantitative data on the development of the WebPEP project. Until the preliminary evaluation report presented in April 2011, the project's initiator, the project leader of ZorgInfoTV, and the project manager of Zorgportaal Rijnmond were primarily interested in numerical data related to live views (see Appendix A, Table A-1). They regarded live interaction with WebPEP participants as a crucial feature of the application, and the number of live views as a rough indicator for this interaction. After the first three webcasts they were disappointed by what they considered as a low uptake of the project. They were aware that part of the live views could be attributed to project stakeholders (who were also invited to view the live webcasts), and that the number of ‘non-professional’ participants was therefore lower than the reported values suggest. Even as a comparative value, these numbers became increasingly difficult to interpret for the project members. Aside from seasonal differences to take into account,¹¹ variations in the number of webcast views could be attributed to an

⁸ The procedure was different during the first seven webcasts, when login took place through the combination of a username and password that were provided to participants in a sealed envelope.

⁹ Aside from a description in the Project Initialisation Document of Zorgportaal Rijnmond, no formal documentation was available on WebPEP.

¹⁰ The first author was at the studio during the preliminary test (August 17, 2010) and for webcasts #1, 2, 3, 4, and 7 (see Appendix A, Table A-1).

¹¹ For example, some project members attributed the decrease of live views between June and August 2010 to the summer holidays.

increasing number of technical variables, such as the introduction of a new authorization and authentication procedure for participants (webcast #8; see Appendix A, Table A-1).

With insufficient quantitative data to provide useful feedback to the CF Team on the uptake of WebPEP, we focused on the content of the information being exchanged between presenters and participants. This would give a first indication on how the application was being used. In terms of knowledge level and tone of voice, the webcast presentations varied considerably between different topics and presenters: some were aimed at ten- to twelve-year-olds (such as the tutorial on nebulization in webcast #6), others were directed at older children. This diversity in the content and presentation of webcasts was intentional. Questions submitted by participants during the live webcasts were equally diverse, and ranged from explanation and information queries to verification inquiries. In the webcast on antibiotics, for example, they asked such questions as “Why do you always have to finish the course of antibiotics?”, “How long can you use antibiotics without becoming resistant?”, and “They say that in Germany there is a substance against pseudomonas infection, is that correct?”

Although the nature of some of the submitted questions was indicative of children’s active participation, throughout the first four webcasts it was clear that questions were also being raised from the parents’ perspective, or that they reflected parental concerns. In some cases it was self-evident that parents were submitting questions (e.g., “My three-year-old son...”). We shared this insight with the project members, as the active participation of parents had not been anticipated or taken into account in the early development stages of WebPEP.

Project Members’ Assessments

Different stakeholders in the project assessed the user uptake of WebPEP differently. On the one hand, the project leader of ZorgInfoTV and the program manager of Zorgportaal Rijnmond focused on volume, and grew increasingly concerned about the legitimization of WebPEP in terms of cost-effectiveness. They expressed doubts on the viability of WebPEP over a longer period of time, given the production costs¹² and the number of live views that the webcasts were generating. They also questioned whether the full potential of the ZorgInfoTV application would become visible through the pilot, as it was solely focused on CF patients. They argued that a more widespread chronic disease—such as diabetes—would have given access to a larger population, and that it would have allowed for more extensive patient participation.

Stakeholders related to the CF Centre, on the other hand, were more preoccupied with the apparently lacking impact of WebPEP among its prospective users. As a first reaction, the project’s initiator sought ways to make the webcasts more appealing to children aged twelve to eighteen. Among other things, he requested a playful template design for the PowerPoint slides, introduced the use of a graphic tablet in his own presentations, and organized training sessions for presenters. His assessment of WebPEP differed from that of the project leader and the program manager in that he sought different ways to use WebPEP as an educational tool. After the preliminary evaluation report issued in April 2011 (in which we signalled a rift between prospective and actual users), the initiator gradually attributed more importance to the number of ‘on demand’ views (see Appendix A, Table A-1). He perceived the overview of these cumulative values—which was updated in each webcast report—as a positive indicator for the participants’ interest in the WebPEP video library.

Participants’ Views

When the preliminary report was issued, little was yet known about the participants’ views on the project. Interviews with participants were conducted after the eighth webcast. The CF Team had provided a list of ten telephone numbers of patients who periodically received invitations to WebPEP; about half of them were adolescents. Difficulties were experienced in recruiting adolescents with CF as respondents. Most claimed that they had never heard of the project; two vaguely recalled the invitations that had been sent to them, but only one agreed to participate in the study. As one sixteen-year-old stated in a telephone conversation with the first author: “I can’t identify with it [the WebPEP project] at all.” The adolescents who claimed to be unfamiliar with WebPEP either said that they had no intention of attending future webcasts, or that they were unlikely to do so. Other patients on the list were either too young to consent for an interview, or too young for WebPEP; in both cases, the first author spoke with their parents.

Interview respondents were two patients aged ten and fifteen, ten mothers, and one father.¹³ They were recruited from the aforementioned telephone calls, as well as at the parents’ meeting. The children gave their views on the application in terms of usability, “look and feel,” and the quality of the presentations. The parents talked about the

¹² The production cost per webcast was approximately 5,000 euro.

¹³ The parents’ children were under the age of six.

“usability” of the application, the quality of the presentations, the duration and scheduling of live webcasts, the respondents’ expectations of CF education, and their practices in gathering information about CF.

Both patients had been persuaded by their parents to participate in WebPEP webcasts. They struggled to think of the “added value” of WebPEP in their lives, and emphasized what they were missing from the application instead. One suggestion related to the degree of interactivity of the application, which the fifteen-year-old respondent perceived as too limited. When asked what he would change about the webcast, he said:

“Perhaps that people who gave a presentation stay online. Or that they log in occasionally. So that questions can be asked to them. That they answer on a later date. Because sometimes you don’t get an answer to your question. [...] I think the specialist is the best person to answer those questions.” (CF patient, aged fifteen)

He also gathered that his questions on CF would be too specific to be of interest to the other participants during the presentation; his suggestion to extend the opportunity to submit questions after the webcast must be seen in this light as well. By contrast, the ten-year-old respondent was too young to have clear questions of her own; she explained that she watched the webcasts together with her mother, who clarified some of the difficult points for her along the way. While both were sympathetic toward WebPEP, it was difficult to determine to what extent they identified with its educational purpose.

Parents of young children who participated in our study were overtly enthusiastic about WebPEP. Most of them experienced difficulties in gathering reliable information on CF. They distrusted many online sources on CF, and some had grown discouraged by the very practice of seeking CF information online, which often led them to upsetting accounts about terminally ill or deceased patients, and made them worry about the prospects of their own children. They described WebPEP as having a positive approach to therapy, as well as a reassuring effect on participants. Furthermore, they appreciated the opportunity of having direct interaction with a specialist rather than with a nurse of the CF Team. Several parents complained that the nurses tend to act as “gatekeepers” between specialists and parents when they contact the CF Centre by phone: aside from the face-to-face consultations at SCH, parents rarely get to speak directly with a specialist.

While some parents of young children used WebPEP’s interactive functionalities for this very purpose, not every respondent felt compelled to do so. One parent explained his reluctance to ask questions through the application as follows:

“I think it’s a personal thing... my wife and I, perhaps we’re not the kind of people to easily engage with that sort of thing? I’m not exactly sure what it is... just like with social media, some use Twitter very actively and others don’t, that’s how I’d explain it, some ask questions very easily, and we don’t. [...] We’re more or less sitting there as spectators, you know? Of course we don’t have the disease... sure, we do give guidance to our son, he needs our help, but still you’re also sitting there as a spectator, to some extent. You learn most from kids who are a little older, and the questions they ask.” (Father of a five-year-old boy with CF)

This example shows that users engage with technology in very different ways. A commonality among parents with young children is their perceived knowledge deficit in CF education, which they related to their own insufficient experience, and to the lack of an extensive peer network. One parent viewed the “social” component of CF education as something that could be further explored in the WebPEP project:

“I guess we are also looking for support groups. [...] In any case it’s difficult to get in touch with people living nearby. You can check on CF-Café [an online forum for CF patients], but even so, there are not that many people [dealing with CF] in my area.” (Mother of a two-year-old boy with CF)

The importance of expanding one’s social network was also emphasized by a mother of adolescents, who argued that parents gradually learn about CF as their children grow older, and that it takes time for their peer network to grow. In her view, educational projects such as WebPEP are less interesting to parents of older children, such as herself:

“I noticed that in the presentation about the lab, I already knew several things... and there are many people asking a question, and then I think well, that was already explained, or I already know what the answer is. [...] I thought it looked nice, that’s not the issue, and especially for them [her children]... and a lot of information was given on the topic, so that was good. But for me it would have to go a step further. And that’s difficult. So you shouldn’t look at me, but at them [the children].” (Mother of fifteen-year-old twins with CF)

As a mother of adolescent children, this respondent felt that the educational character of WebPEP was not directed at herself. And indeed, the project had not been conceived to educate parents. Yet overall, parents of young CF patients regarded WebPEP as a “welcome addition” to their lives, and voiced the hope that the project would be carried on indefinitely. With this, they expressed a need for more education targeted at parents of young patients.

Reframing the Project

The final evaluation report was issued in August 2011 and marked the end of the evaluation period. Perhaps more importantly, it also actively contributed to the reframing of the WebPEP project. In a plenary presentation at SCH in October 2011 we used the report to highlight the observed rift between prospective and actual users, and to emphasize the value of WebPEP to parents of young CF patients. The needs of the latter, however, were not the main priority of the project’s initiator. In reaction to the findings in our report, he commented that the video library could serve as an important resource for members of the CF Team, and that WebPEP should become an extension of their work routines. He made the following suggestion:

“One of the things, and that relates to your work process [speaking to the members of the CF Team], is that we should put up something like a poster of available webcasts, so that during a consultation you remember to say ‘we talked about this subject, perhaps it’s a good idea if you take a look at the broadcast’.”

One member of the CF Team added that they already started referring patients to WebPEP whenever possible. She gave the example of a young patient who visited the SCH, and who feared the annual clinical examination: they advised the patient to watch the webcast entitled “Less Afraid to the Hospital” in the video library. Another CF Team member stressed the importance of integrating WebPEP in their own routines toward patients:

“With new children we can inform them right away [of the existence of WebPEP] so that they are accustomed from the start: ‘now I give you a lot information, but you can look up some of that information later on’.”

When the members of the CF Team were asked how they thought WebPEP could reach out to adolescents, one of them argued that the application looked too dull, and that it required a visual overhaul. The initiator disagreed that this would solve the issue. Drawing from the comments and suggestions made in the final evaluation report, he commented as follows:

“Still, I don’t think that’s the point. They are watching flashy things all day, in which all kinds of things happen; I’m afraid it makes this [WebPEP], relatively speaking, an old medium.”

Nevertheless, the CF Team felt it had to make more efforts to appeal to adolescents by working within the boundaries of the application, rather than to discard it. One of the suggestions made at the end of the meeting was to invite adolescents to present a webcast, or to have them participate in the production process. The type of information being exchanged and the degree of interactivity were to be left unchanged; the implicit expectation was that WebPEP could thus continue to serve as an educational program centered on youth.

In the following months an extra series of WebPEP webcasts was financially secured by the CF Centre. A total of 23 webcasts were produced between November 2010 and December 2012. Throughout this period the frequency of webcasts decreased, but the setup and presentation (targeted at children over the age of twelve) largely remained unchanged.¹⁴ Themes continued to relate to therapy adherence and social aspects in CF, and questions from webcast participants were predominantly about young children with CF. Some webcasts now featured a young assistant in the role of moderator.

The reframing of WebPEP as a resource for members of the CF Team underscores that online education was predominantly viewed by the latter as the act of “sending out information to patients.” We found that knowledge exchange between presenters and participants was a subdued part of the CF Team’s rhetoric, and that live webcast interaction was to a large extent controlled by the presenter and the moderator. This control over the interaction, as well as the act of “sending” or “transmitting” information to an audience, was deeply inscribed in the ZorgInfoTV application. The technical arrangement of visible presenters interacting with anonymous participants allowed the project to comply with ethical guidelines in Dutch healthcare, but it also enabled and sustained the central position of the presenter during the live webcasts—much as in the academic settings for which the product had originally been developed by the vendor. Throughout the evaluation period this feature of the application was left unchanged; it was the embedding of WebPEP in the educational strategy of the CF Centre and its relation to the “end user” that was

¹⁴ Webcast #11 (see Appendix A, Table A–1) was explicitly directed at the parents of young patients.

significantly transformed. The following discussion focuses on this “reconfiguration” of WebPEP and its users in relation to the goal of providing patient-centered education.

VII. DISCUSSION

The lacking participation and disqualifying comments made by adolescent patients in relation to the project show that the educational strategy envisaged by the CF Centre through WebPEP did not resonate well with its prospective users. The two patient-users interviewed during the evaluation felt that the application was insufficiently interactive, and made suggestions to improve the content; “non-users” felt no connection to the project, and did not feel compelled to participate in the study. Consequently, little is known about their thoughts and feelings about CF education, or their motives for not participating in this project.

Parents of young children embraced WebPEP, emphasized its added value to them, and were decidedly less critical about the technical limitations of the application. An important difference in their relation toward the project may reside in its disciplining character (described as “striking the right chord” by the project’s initiator). Although the children did not comment on WebPEP in these terms, it can be assumed that the application acted as an undesired or uncomfortable reminder of their chronic condition. Parents are also affected by the highly elaborate regime of therapy and exercise that WebPEP prescribes, but they are not physically subjected to it. They engage with the program as a source of information on their children’s condition, not their own. Through WebPEP they acquire knowledge that can assist them in their caring tasks, and that allows them to enact responsible parenthood.

The fact that one webcast participant described himself as a “spectator” underscores the differences between the intended use of the application (interacting with the presenter via the text box) and people’s practices—how they think about their relation to the application, and how they engage with it. The parent who expressed his reluctance to submit questions to the presenter effectively bypassed the “interaction” script of WebPEP by watching the webcasts as if they were television broadcasts: to him, the main value of WebPEP resided in the questions raised by other participants.

The WebPEP project had been envisioned and developed from the CF Team’s (perceived and argued) need to educate patients. Through the application, the user was originally configured as an active child who participated in his or her own treatment. However, this assumption did not match with the attitude of the majority of prospective WebPEP users—patients between the ages of twelve and eighteen who discarded repeated invitations to participate. The initiator’s reflection that the problem resided in the type of medium, rather than its “look and feel,” evades the question whether these patients were at all open to participate and to actively contribute to a voluntary educational program. From the start, the project’s initiator acknowledged that adolescents are a “difficult” age group to reach out to; however, little was known about their own perspectives on CF education before the project started. A better understanding of the vantage point of WebPEP’s prospective users could have directed the project members toward a different type of educational instrument altogether.

Although the non-use of WebPEP among children and the participation of young patients’ parents did not lead to major changes in the format of the application, both elements played a catalysing role in the reframing of the project. While data on non-users were too scarce to be analysed in the final evaluation report, the project’s initiator acknowledged their significance. His reframing of WebPEP entailed less focus on its interactive character, and a stronger emphasis on its supporting role to the CF Team in their consultations with patients. As a more active role was envisioned for CF Team members in directing patients to relevant webcasts in the video library, the user was reconfigured as a more “passive” information recipient.

This finding coincides with Sassene and Hertzum’s assessment of an application designed to improve asthmatics’ self-management: its prospective users were reluctant to adopt it, and the application became an “extension of healthcare professional’s views on asthma and its treatment” [Sassene and Hertzum, 2009]. Their study implicitly shows that modifying an application to accommodate reluctant prospective users is a difficult, if not impossible, task. In light of their assessment—which focuses on the patients’ performativity of asthma and subsequent incompatibilities with the application—Sassene and Hertzum suggested that “the development of self-management systems may benefit from a more thoroughly user-centered approach” [Sassene and Hertzum, 2009]. In the wake of Haraway [1991], they argued that users have the “ability to accommodate multiple, simultaneous performances” [Sassene and Hertzum, 2009], and that designers of e-health applications must be more sensitive to practices and performances of illness, and to what feels good/pleasant and bad/unpleasant to the patient [Sassene and Hertzum, 2009]. Their central argument is that patient-centered applications require patient-centered design and development.

Oudshoorn and Pinch point out that understanding the role of users in technology “requires a methodology that takes into account the multiplicity and diversity of users, spokespersons for users, and locations where the co-



construction of users and technology takes place” [Oudshoorn and Pinch, 2005]. The formative evaluation as applied in the WebPEP study can give a voice to patients, and allows researchers to forward feedback from actual users to project members during the development. In the case of WebPEP, however, the research intervention did not counter the problem identified by Sassene and Hertzum, and came too late to revert the technical setup and content of the application.

The approach suggested by Oudshoorn and Pinch requires the consultation of prospective users prior to the design stage of the project—an insight that aligns well with Wilson and Lankton’s framework for making early predictions about patients’ behavioral intention toward e-health use [Wilson and Lankton, 2004, 2009]. Indeed, if the WebPEP application qualifies as an example of patient-centered e-health (PCEH) in terms of its espoused goals [cf. Dawson et al, 2009], its design, development, and execution suggest that *practicing* PCEH requires insights in the actual use of technology [cf. Oudshoorn and Pinch, 2005]. Attempts to increase the number of users [cf. Oudshoorn and Pinch, 2005] during the course of the pilot were unsuccessful and were followed by a reframing of the project. The relation between WebPEP and its end users was transformed through the introduction of an alternative script, in which the application served as a resource for CF education and as an extension of the CF Team’s education program. In this process, members of the CF Team became more visible in their role as users of the application, without it compromising the participation of active patients and parents. The reframing entailed a different way of practicing patient-centeredness: one that was more attuned to the act of “sending out information to patients,” and that was less preoccupied with inciting their active involvement. The project’s initiator was no longer concerned with volumes of patient participation, and ascribed new legitimation for the project to the use of the video library. He now explicitly advanced the supporting role of WebPEP for the CF Team; this role was translated in the practice of referring patients to webcasts for further information. Whenever deemed necessary or relevant to their specific needs or situation, patients were directed to specific webcasts in the video library.

VIII. CONCLUSION

Our study suggests that when an e-health application fails to reach out to prospective users, this does not necessarily entail the project’s failure. Without resorting to significant technical modifications, a reconfiguration of the application and its users can give new legitimation to the project. In the case of WebPEP, this reconfiguration implied an alternative way of integrating patients in the CF Centre’s education strategy. While the application continued to offer the same webcast functionality directed at children between the ages of twelve and eighteen, the ability to refer patients to the video library served as an important new attribute to the CF Team. The increasing number of recorded webcasts enabled WebPEP to become a repository for “reliable” knowledge about CF.

The WebPEP case illustrates how a single technological artefact was involved in different, coexisting practices of patient-centeredness. Although the application did not produce a symmetrical knowledge exchange between webcast presenters and participants, the CF Centre’s act of inviting patients to learn more about their condition (in the interest of their own well-being) legitimized it as a form of patient-centered e-health. Meanwhile, the video library was used by the CF Team as a means to structure the CF Centre’s education strategy, and to expand the knowledge base at the patient’s disposal. These practices entailed different enactments of PCEH: attempts to “empower” patients went hand in hand with efforts to provide patient education in a coherent, comprehensive, and “tailored” form.

The lacking participation of adolescent patients in WebPEP points to the importance of giving an active role to users and non-users in the design and development of PCEH applications. Although we were unable to explore their viewpoints sufficiently, we stress that understanding people’s desires, motives, needs, and practices in relation to their own health and illness is crucial to PCEH. When applied from the earliest phase, formative evaluation methods can contribute to anticipating the use of PCEH applications and help in configuring the user in the process. Insights generated by this methodological approach are relevant to both design and development, and can allow for timely, pragmatic interventions.

IX. KEY RESULTS AND ARGUMENTS

- Our evaluation showed a rift between prospective and actual users in the WebPEP project;
- Reconfiguring the application in relation to its users gave new legitimation to the project;
- A single technological artefact can be involved in different, coexisting practices of patient-centeredness;
- Different practices of patient-centeredness entail different enactments of PCEH;
- Formative evaluation methods can help in configuring the user in the design and development of PCEH applications.

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Editor’s Note: The following reference list contains hyperlinks to World Wide Web pages. Readers who have the ability to access the Web directly from their word processor or are reading the article on the Web can gain direct access to these linked references. Readers are warned, however, that:

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APPENDIX A: TABLE AND FIGURES

Table A-1: Webcast Topics and Number of Views per November 17, 2011

Title	Description	Live	On demand
Drugs and Compliance	On CF medication and the importance of therapy compliance. Presented by a pediatrician specialized in pulmonology (A) November 17, 2010	22	84
Enzymes, etc.	On enzymes and how they work. Presented by a pediatrician specialized in gastrointestinal and liver diseases (A) December 16, 2010	25	70
Where Does Slime Go When You Swallow It?	On the physiology of lungs and breathing techniques. Presented by a children's physiotherapist January 27, 2011	35	59
What's Growing in My Sputum	On the characteristics of bacteria and the prevention of infections. Presented by a medical microbiologist February 24, 2011	49	48
Less Afraid to the Hospital!	On the various steps that a young patient undergoes during the yearly check-up. Presented by a health psychologist March 31, 2011	15	51
How Do Drugs Enter the Lungs?	On nebulization instruments and techniques. Presented by a pediatrician specialized in pulmonology (B) April 28, 2011	11	53
Antibiotics	On antibiotics and whether they can be harmful. Presented by a pediatrician specialized in pulmonology (A) May 26, 2011	18	35
Obstipation	On obstipation, its causes and remedies. Presented by a pediatrician specialized in gastrointestinal and liver diseases (B) June 30, 2011	4	41
Why Breathing for Lung Function?	On the importance of lung function tests. Presented by a pediatrician specialized in pulmonology (C) August 25, 2011	6	41
What Is DNA?	On chromosomes, DNA, and the hereditary nature of CF. Presented by a researcher in clinical genetics September 29, 2011	2	30
Why the Annual Examination?	On the reasons for yearly physical examinations at the CF Centre. Presented by a pediatrician specialized in pulmonology (D) October 27, 2011	9	9

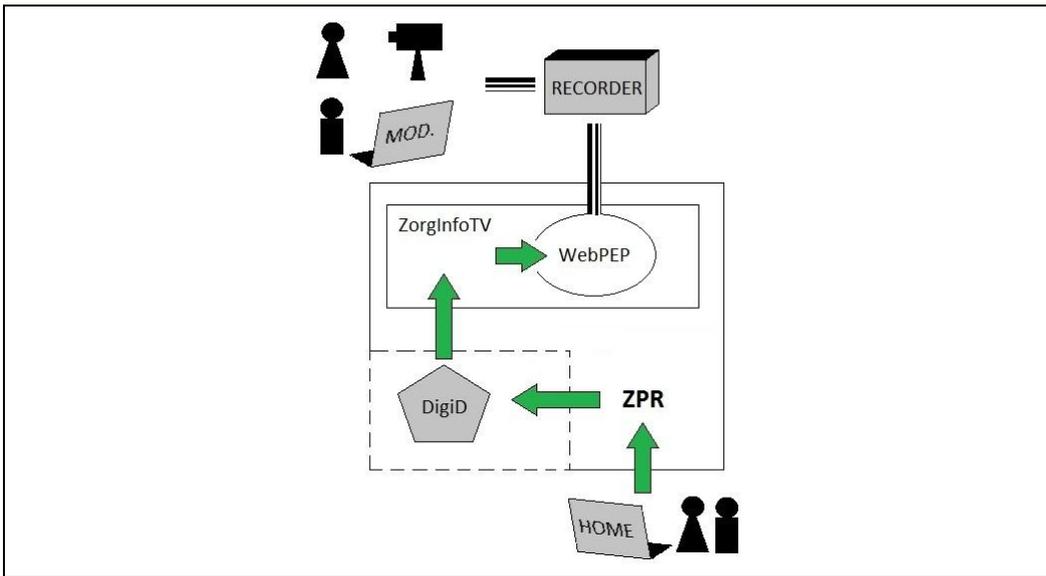


Figure A-1. How WebPEP Participants Log in to the Application

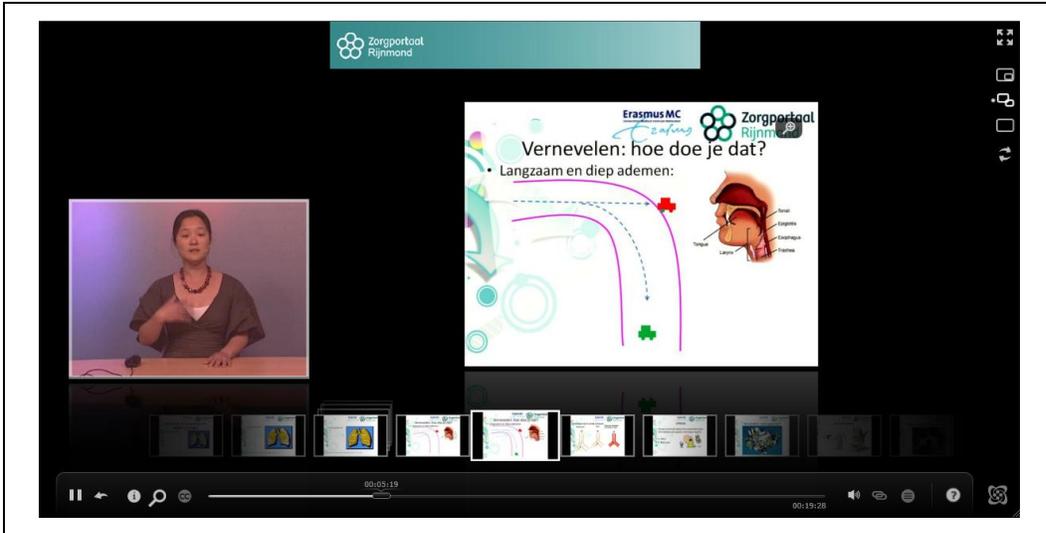


Figure A-2. Screen Capture of the WebPEP Interface (on demand view)

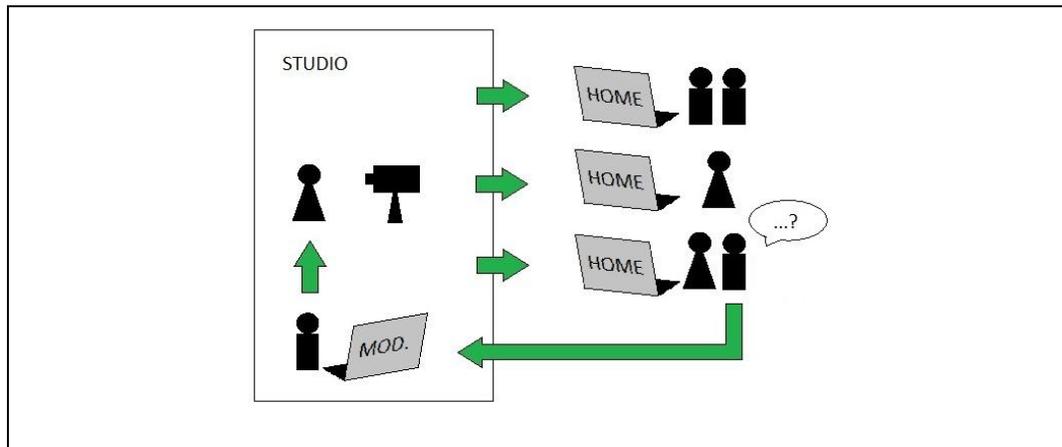


Figure A-3. Live Interaction Between Presenter, Participants, and Moderator

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